

Extracts and plain-language summaries of articles appearing in the
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Global Perspectives on Autism



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Editorial: Perspectives From the Common Ground

Mayada Elsabbagh, Guest Editor



60 researchers and practitioners from 20 countries contribute to a special collection of studies and perspectives on autism research around the globe. Taken together, their contributions demonstrate the value of giving equal priority to advancing scientific discovery while simultaneously addressing the needs of those affected by autism around the world.

It is thought that a form of autism affects 1% of the world's population. This means that many of the world's children who are affected by autism also face issues of survival and physical health. Most live in less-developed countries, where services are limited or not available at all. Poverty, abuse and neglect worsen the negative impact of the condition, despite these factors being preventable. Against this reality, where does the current autism research agenda fit in? Global research often focuses on improving the response of the health care system to neurodevelopmental conditions, including autism. However, most research on autism is concerned with scientific discovery, through understanding the characteristics and causes of the condition in many different settings.

In this editorial, which introduces the special issue *Global perspectives on autism*, Elsabbagh suggests that global research needs to give equal priority to advancing basic research and to improving the lives of those affected by the condition. If autism research continues to be conducted in a way that is detached from real-world settings then effective translation of research knowledge will be very difficult. Similarly, if the immediate goals of improving the lives of those affected overshadow the need to understand underlying causes and to isolate reliable biological markers, limited progress will be made in the long run. Experiences of researchers featured in the special issue offer examples of finding the common ground, where these priorities are balanced. In closing, Elsabbagh stresses the need for partnerships among researchers, families, and health workers in moving global autism research forward.

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Global Prevalence of Autism and Other Pervasive Developmental Disorders

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In preparing a report to the World Health Organization, researchers from 10 countries systematically reviewed all available evidence on the global prevalence of autism. Their findings bring to light studies rarely considered in previous research.

Why was this systematic review done?

There is a great increase in the amount of research being done on autism in the last few decades. However, there is still little information available about the impact of the condition on most of the world's population. Knowing the prevalence of autism – or the number of cases of the disorder at a given time within a population – is key to furthering research and developing policy and services for the disorder that match the needs of those affected. This systematic review was based on a report commissioned by the World Health Organization to address the question of global prevalence of autism.

How was it done?

In addition to reviewing studies from conventional sources, the authors identified country- or region-specific publications using a wider range of search engines including those in languages other than English. They also consulted with local researchers and practitioners to ensure that no studies were missed. This resulted in over 600 studies that were evaluated by the authors, who then selected a subset that was deemed adequate to provide estimates of prevalence. The studies were not always comparable. Prevalence estimates are affected by the fact that the definitions of autism have changed over time. The studies also differ in how they find their participants and what assessment tools and measures they use to evaluate them.

What did we learn?

The prevalence of all forms of autism combined is estimated to be 1 in 160 individuals, using studies conducted from 2000-2011 in different areas and by different researchers. This is an average figure and there are many differences across studies. Therefore, the authors stress that this figure does not strictly represent a world-wide estimate, but instead, a general reflection of the current state of evidence from different areas of the world. The review highlights that most studies have been done in high-income countries. For many world regions, prevalence estimates are not available or very limited. The review confirmed what many people in the community suspect which is that there is a rise in autism prevalence over time. However, the authors suggest that this is primarily due to an increase in awareness, service availability, and the fact that milder forms of autism are being diagnosed more often.

What does this contribute?

This is the first large-scale global systematic review of prevalence estimates with a particular focus on world regions that have not been previously considered. The authors advocate that although prevalence studies tend to be costly, they are very powerful tools for advocacy and evidence-based policy because these studies can

- Assess needs and priorities within communities
- Provide information about availability and quality of services
- Improve training and services because the research often requires use or development of diagnostic tools
- Help in determining the true global burden of autism and how its impact varies under different social and economic conditions.

Screening for autism in Mexico

*Eric Fombonne**, Carlos Marcin, Ruth Bruno, Cecilia Manero Tinoco



Christian Diaz Marquez²

As part of the first epidemiological study of autism in Mexico, researchers showed that a short parent- and teacher-completed screening tool can effectively support recognition of symptoms in school children.

Why was this study done?

Though many advances have occurred in screening practices, the methods need to be adapted to specific communities. In their efforts to conduct the first epidemiological survey of autism in Mexico, the researchers recognized that there is a need for a screening tool to detect childhood autism symptoms in that country.

How was it done?

The research team chose the Social Responsiveness Scale (SRS) as a screening tool because it has been widely used, it is easy for teachers and parents to complete, and it is effective at detecting many key signs of autism. The Spanish SRS had not previously been used in Mexico.

The study included over 500 school-age children in Mexico. The researchers compared those diagnosed with autism to typically developing children. The parents and teachers of the children were asked to complete the Spanish SRS. Scores of the SRS provide a measure of autistic symptoms and social impairment including social awareness, social cognition, social communication, social motivation, and autistic mannerisms.

What did we learn?

The overall SRS was effective at detecting school-aged children with autism when used by parents and teachers. It was also effective on all 5 other scores as well, for both SRS users. Based on these results, the Spanish SRS appears to be a useful screening tool for identifying autism in Mexico.

What does this contribute?

Researchers have validated a tool that can effectively screens for autism in Mexico, where there was no such tool available in the past. Overall, this screening tool was successful in the Mexican study and has the potential to be adapted across similar cultural settings. This study represents an important step in improving worldwide screening for autism.

Challenges, coping strategies and unmet needs of families with a child with Autism Spectrum Disorder in Goa, India

Gauri Divan*, Vivek Vajaratkar, Miraj Desai, Luisa Strik-Lievers, Vikram Patel



In mapping community needs in Goa, India, researchers elucidate the heavy burden on families and those who support them.

Why was this study done?

Autism is increasingly recognized in developing countries like India. However, little is known about the experiences of parents raising a child with autism. Parents and other caregivers of children with autism face many social and emotional challenges, and different parts of the world have their own unique experiences with these. This study explored these challenges, and ways that caregivers in Goa, India, make changes in their lives to meet these challenges.

How was it done?

Twenty interviews and nine focus group discussions were carried out with families of children with autism and key community members such as special educators, teachers, and parents of typically developing children. Close to 100 people in total participated in the study.

What did we learn?

Raising a child with autism in Goa puts a great strain on families, often negatively affecting parents' health and relationships with others in the community. The impact of raising a child with autism extends into school and the wider community, with little awareness of autism and some negative experiences of discrimination being reported. Obtaining professional help is often quite expensive, requiring long trips to larger cities; and getting a correct diagnosis is frequently difficult. However, there were also positive experiences with professionals, especially special educators. Though parents and professionals reported significant hardships, parents found strategies to cope including: going back to work, selectively disclosing to close family, finding religious help, and gradually reintegrating into community networks.

What does this contribute?

The study is the first to systematically collect information from families and professionals in Goa and map their unmet needs. Two key strategies can be implemented to support these needs:

- Raise awareness of autism and its impact on families to help reduce misinformation and stigma and facilitate early detection. Parent support networks can help in this process by empowering and strengthening families to challenge discrimination.
- Early diagnosis supported by low cost evidence based interventions need to be made available, so that these "packages of care" can be delivered by trained community health workers and parents.

Read the full article: <http://onlinelibrary.wiley.com/doi/10.1002/aur.1225/abstract> *Correspondence to gauridivan@gmail.com

“Communities” in Community Engagement: Lessons Learned from Autism Research in South Africa and South Korea

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Engaging communities in research in South Korea and South Africa helped to find supportive solutions for children with autism, while also increasing knowledge of the cross-cultural aspects of the condition.

Why was this study done?

Community-based research requires collaboration with the population where research is conducted. There is no one-size-fits-all method of community engagement. There are many language and cultural differences between communities, and many do not trust researchers – but for different reasons. Successful community-based research requires knowledge about how the burden of care is distributed amongst family members, what families know or understand about services, and their ideas of advocacy and treatment. The researchers in this study explored community engagement as part of ongoing studies in South African and South Korea.

How was it done and what have we learned?

South Korea. A recent prevalence study was launched in South Korea with the hope that it would help increase awareness, decreasing stigma, and expand special education services in the country. Screening by means of community engagement gave more accurate prevalence data than what would have been ascertained by exclusively using health records. The community-based methods used in this study allowed researchers to identify otherwise unrecognized high-functioning ASD children. In the study, families and teachers expressed their mistrust of the medical community, and fear of stigma and loss of confidentiality. The researchers employed ethnographic interviews and focus groups in order to address these concerns, which had contributed to the under-diagnosis of the condition.

South Africa. Researchers used methods of community engagement to reach low-resource and underserved populations in a KwaZulu-Natal (KZN) autism screening program. As in many low- and middle-income countries, early intervention for ASD is often neglected, as resources are focused on short-term survival issues. During the course of the research, interviews were conducted with parents, teachers, health care professionals, traditional healers, and clergy. These interviews explored what services are available, what should be included in the research materials, and how to translate the screening and diagnostic tools. Involvement of bilingual (Zulu/English) parents supported accurate language and cultural relevance of the evaluation tools used in the study.

Two important barriers to community participation in South Africa were poverty and the AIDS epidemic. Poverty limited the ability of parents to seek ASD-related medical attention unless symptoms were severe. Many children were being cared for in centres called *crèches* where awareness of autism was very difficult. HIV/AIDS often complicates recognition, as it can result in developmental delays. An important contribution of the study was the openness in discussing the topics addressed. Participants reported feeling inspired to continue discussions and build social networks to deliver better care. However, they questioned the value of an ASD diagnosis if there are few services available for treatment. Some also questioned the benefits of a “western” diagnosis vs. a “traditional” diagnosis.

What does this contribute?

There is a clear need to challenge the idea of culture being a *barrier to overcome* in research. Rather, culture can be the key to finding effective solutions for communities. Community engagement as a tool to consider culture

in autism management is equally important in high-income countries. Community-based research provides opportunities to improve research processes as well as to produce meaningful solutions for communities in need.

Read the full article: <http://onlinelibrary.wiley.com/doi/10.1002/aur.1229/abstract> *Correspondence to amy.wetherby@med.fsu.edu

A global public health strategy for autism spectrum disorders

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The charity Autism Speaks launched the Global Autism Public Health Initiative (GAPH) to help develop global autism awareness, research, training and service delivery. They are hopeful that its adoption worldwide will provide solutions to individuals with ASD and their families.

Launched in 2008, the Global Autism Public Health (GAPH) Initiative is an international science and advocacy effort for the development of public health policies and effective programs for autism awareness, research, and service delivery. The initiative is built on five strategies that can be flexibly applied in different countries:

1. Creating a National Advisory Committee to find out the specific needs and opportunities available to set up awareness and intervention programs.
2. Launching a locally-appropriate awareness campaign about signs and symptoms of autism to reduce the stigma and misinformation.
3. Collecting data about the needs of the community and the prevalence of autism.
4. Supporting evidence-based clinical and educational services as well as conducting research.
5. Evaluating solutions for suitability of efforts in each specific socio-political context.

In the last three years, GAPH has set up partnerships in 20 countries. For example, the initiative was launched in *Albania* in 2008 in partnership with the Albanian Children Foundation. Autism awareness in Albania was already high due to the Foundation's prior four years of awareness campaigns. The committee supported the development of a resource library and a number of professional conferences. It has also launched pilot programs to train clinicians and parents in providing evidence-based autism intervention.

Launched in 2011, the GAPH in *Bangladesh* led to the formation of a National Advisory Committee. The initiative hosted an international conference. Alongside the conference, training was provided to both parents and professionals who work with children with ASD. The impact of the initiative was felt in the region as a whole. A number of South Asian countries adopted the Dhaka Declaration on Autism Spectrum Disorder and Developmental Disabilities which calls for more international support for autism services.

The GAPH initiative highlights key challenges in implementation of evidence-based practice. There is a large disparity between global needs and capacity to meet these needs. Socio-cultural and Language differences between countries present significant challenges in developing educational and training programs. Efforts to translate conventional diagnostic tools or to adapt educational or intervention programs designed in the US need to consider cultural relevance in themes and practices.

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Autism and the Grand Challenges in Global Mental Health

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A diverse group of researchers and practitioners offer suggestions for how a truly global approach can bridge knowledge gaps leading to substantive improvements in quality of life for those affected, especially in the world's most under-resourced settings.

Recently, partnership among leading funders and academics has given rise to the Grand Challenges in Global Mental Health initiative, aiming to reduce the global burden associated with mental and neurological conditions. Among the actions of this initiative was a priority-setting exercise to articulate the most pressing challenges research this area needs to address. To meet the grand challenges in global mental health, autism research will need to characterize genotypes, phenotypes, and risk factors in autism across diverse geographical settings, develop culturally appropriate, valid, and comparable diagnostic instruments, and design affordable care packages for use by community health workers, applicable to a range of neurodevelopmental disabilities.

A recent rise in national, regional, and global research and practice networks has given new impetus to this area and created promising opportunities for research. It will be critical for these autism initiatives to forge alliance with global networks already achieving these goals for a wider range of disabilities. In view of the increased awareness of autism worldwide and the growing interest from a wide range of stakeholders, research in this relatively narrow field may be viewed as a potential vehicle for improvements in evidence and practice standards not only in autism, but more generally in child mental health.

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